Dancing with a Syrinx, by Shelley Minturn

I was diagnosed with Syringomyelia and Arnold Chiari Malformation (1) in November of 2002. A series of previously unexplainable falls, continued sinus problems, headaches, lower back and leg spasms were finally justified as something other than “hypochondria” (actual doctors notes in my files).

I have probably had this disorder for most of my life and just wasn’t aware. A pronounced scoliosis curve should have been a red flag, but we lived in a farming community way back then, and the local clinic wasn’t much. I grew up, joined the military and met my first husband. We saw the world together and had three kids, losing our infant son in 1985 after a hard fought illness. Our two daughters (Joye and Hope) grew into talented young women even as our twenty-year marriage fell apart. They saw the signs before I did, both for the marriage and the illness. In my pain and depression I had decided to move on, but it seemed God had other plans!

Thomas came into my life as a sort of blind date. He was there to fix the computer, but he ended up fixing a bitter and broken heart. We were married not long after my divorce became final, and in many ways are still as happy as when we first met. He is my rock; he is a caring, sensitive guy. He is a great stepfather and my best friend-also a world class Grandpa! We had been married a little over three years (how time flies!) when my health took a turn for the worse. It was his familiarity with pain, medicines and surgeries that held me together through all of the trials and testing. But even he was shocked to hear about something called Syringomyelia-it was the first time either one of us had ever heard the word.

Still, finding a name for the condition didn’t quite explain what it was about. Each succeeding physician confessed to little or no experience with syrinxes. They chose to overmedicate it instead. I was lucky not to become addicted! Shots, Patches, pills and pain became my normal routine. My husband and I found our answers finally in a reference book at the local drugstore (a single paragraph that sent me into hysteria), and later, online (an excellent group called ASAP). My daughters were terrified they might have inherited the disorder, and (in my oldest daughter’s case), passed it on to my Grandson, Nicodemus (who is a very healthy 2 year old). This has yet to reveal itself, and we remain optimistic.

This first year of diagnosis has been and still is something of a wild ride. My condition continued to worsen, so I had to take medical leave from my job as a prison guard. The entire right side of my body gradually lost all feeling, making me walk and talk like a stroke victim. The muscle spasms grew harder to control as well. My husband, who is also disabled, graduated from college and returned to the workforce, which resulted in our already unusual family life changing again.

My adjustment to this set of physical restrictions and frailties did not go very well. Going from a work schedule to a busy physician appointments list wasn’t helping either. But God and my family got me through it. How can you be depressed when your grandson is smiling at you (along with stealing your cane)? It was a smile that would melt your heart, and it kept me smiling myself.

A new wrinkle labeled “rapid decline” set into motion a frantic search for a neurosurgeon and the local resources had all been eliminated. By trial and error, and asking my new online friends, we netted a referral to a neurosurgeon in the Dallas Metroplex, where we found our man! But other clouds were on the already darkened horizon- my oldest daughter (who is in the Air Force), was scheduled to deploy to Iraq the week of my hastily scheduled decompression! And my sick leave, even with generous donations from the sickpool, was about to run out as well. It looked as though I might get fired before I could apply for disability retirement. To top things off, Tom developed major difficulties at work that only made matters worse. He was only able to take two days off!

I went under the knife not knowing if one daughter had left yet, worried about the teenager, not to mention my poor husband, caught in the middle of it all, praying that my condition would be stabilized. I would spend most of the week alone except for the occasional phone call from family and friends. Good thing too, I looked pretty awful! You get a lot of funny looks in a sickroom that has no cards or flowers! But, as I learned, no visitors means more SLEEP! The one highlight of the week was my military child walking into my room (my much needed eyeglasses in hand)-with the news that she wasn’t getting deployed after all! My prayers were answered. That week was also the longest I have spent away from my husband, and he didn’t like it one bit-he said he couldn’t sleep.

It’s almost six months later, and the hair has grown back over the surgical scar on the back of my head. I had to teach my right side how to work again. It is amazing to actually feel my right hand and foot again after so many months of numbness and unresponsiveness. I’d like to tell you that full recovery was possible… but I am still working on that. The syrinx is reduced by about half and may still go down or even collapse! The family still forgets sometimes that Mom can’t/shouldn’t be doing that - and sometimes, so do I.

Right now the journey is about discovery- which medicines work and which don’t? Which hobbies can stay and which ones get packed up and donated to goodwill? How much can one Gran spoil her boy? How much energy does it take to keep up with him?

There is also the return to norm - the tight budget, the frayed parental nerve endings from dealing with teenaged angst. It is hard to find time to breathe when you are relearning so much at once. I haven’t been an at home Mom for a long time. The gardening calls, with little household chores at every turn. The paperwork tiger (Social Security) still needs taming. It is all done in tiny steps. Right now, the medications work and I’m relatively stable. That’s good enough for today…tomorrow is another day.

Would you like to share your perspective? Submit to: director@conquerchiari.org Type "Perspectives" in the subject line.
